

**CAB Conference Call
June 27, 2013
12:00 EST
Meeting Minutes**

Participants:

Carlos	San Juan Research Hospital
Carrie	University of Colorado, Denver
Cathy	University of Miami
Claire	Harvard University
Delia	University of Miami
Jie	Harvard University
Juan	University of Puerto Rico
Julie	Harvard
Julie	Westat
Kim	Texas Children's Hospital
Kimona	Harvard University
Laurie	FSTRF
Leslie	Texas Children's Hospital
Mariana	University of California – San Diego
Marilyn	Bronx-Lebanon Hospital Center
Mary Anne	Westat
Megan	Westat
Rosetta	Bronx-Lebanon Hospital Center
Theresa	Texas Children's Hospital
Veronica	University of California, San Diego
Yuri	University of Miami

• **APPROVAL OF MINUTES**

The minutes from the May 23, 2013 call were approved with no changes.

• **NEURODEVELOPMENTAL EVALUATIONS**

Dr. Cathy Longa talked about neurodevelopmental evaluations. Neurodevelopmental evaluations are tests that are given to learn more about a participant's functioning in different areas. Psychologists compare a participant's test scores to average scores based on age. The goal is to understand every participant's learning style. Psychologists can point out participants' strengths and weaknesses. The test results help caregivers and doctors to provide appropriate treatment. The test can help doctors better understand their patients. Psychologists can use to tests to find out if a participant has a learning disability or disorder.

In PHACS, psychologists look at how children with HIV-infection or HIV-exposure grow over time. Complete evaluations are given for children ages six and up. Preschoolers are given shorter evaluations. The tests for preschoolers look at emerging skills. Babies and toddlers are given developmental tests. These tests measure how babies are developing in different areas. Psychologists look at their problem-solving skills. They also look at their language skills and their motor skills. Language skills include talking and responding to others. Motor skills include crawling and walking.

Tests for babies and toddlers are given every six months. Tests for children are given about every two years. Tests for adolescents may be given at major life transition points. This may include starting high school, college, or a job. Tests may also be given when a young adult is transitioning from pediatric to adult care. Psychologists may meet with participants once a year to see if testing is needed.

Tests are given by a psychologist with specialized training. Psychologists get information from many sources. They talk to caregivers about the child's history. They talk to teachers about how the child is doing in school. The psychologists also talk to doctors about the child's medical history.

Psychologists are mainly looking at cognitive functioning. Cognitive functioning is how a person thinks, learns, and solves problems. Psychologists look at many areas like intelligence, language, memory, and attention. They also look at visual, motor, and academic skills. Screenings may also be given for behavioral and emotional factors.

Intellectual ability (IQ) can be calculated by many subtests. Some tests are verbal with oral questions. This means how a child responds out loud to a question. Some tests are visual and involve solving puzzles and problems. These tests may have time limits. These tests look at verbal and non-verbal functioning. Psychologists compare participants' scores to average scores of children of the same age. IQ may be a predictor of school achievement.

Psychologists look at language. Language is the ability to understand and communicate with others. The two areas are receptive language and expressive language. Receptive language is how well a person can understand what they hear. This can include following directions. Expressive language is how well a person can express themselves. This can include vocabulary skills.

Memory is also tested with neurodevelopmental tests. Psychologists look at verbal memory and visual memory. Verbal memory is how well a person can remember what they hear. Visual memory is how well a person can remember what they see.

Tests may also be given to look at attention. Attention is how well a person can focus on one task. These tests can find out if a child is having trouble with concentration. The psychologists look at auditory attention and visual attention. Auditory attention is a person's ability to pay attention to oral material. This can mean paying attention to a lecture. Visual attention is a person's ability to stay focused and finish a task. This can mean finishing homework.

Psychologists also measure executive functions. Executive functions are skills that control behavior and thinking. Executive functions are skills in planning, problem solving and stopping and starting actions. These skills can help with organization.

Some tests look at visual and motor coordination. Psychologists look at visual perception and motor skills. Visual perception is how well a person can organize what they see. Visual perception is important for math. It is also important for understanding graphs and directions. Motor skills are how well a person can coordinate small muscles in their body.

Psychologists also look at academic skills. They look at reading, math, and writing skills.

The tests are scored after all information has been collected. Psychologists can point out a participant's strengths and weaknesses based on the participant's scores. Psychologists write a detailed report. They talk about the report with the caregiver. Psychologists may give recommendations for the participant's treatment. They provide support and answer questions.

• **PHACS CAB EVALUATION SURVEY RESULTS**

Megan talked about the PHACS CAB Evaluation Survey results. There were 7 responses. Some suggested topics for upcoming calls are:

- Neurodevelopmental studies;
- New laws;
- Bad relationships and how they affect self-esteem and health; and
- Updates from other studies.

- **CAB SPOTLIGHT – SITE 19 – TEXAS CHILDREN’S HOSPITAL**

Kim talked about the site CAB at Texas Children’s Hospital. There are about 15 members. Two CAB members started an organization called, “Positive Play Date.” Positive Play Date sets up play dates for children who are HIV-infected. Play dates are also set up for parents who are HIV-infected. It is a safe environment for people to meet and play. Children in the CAB recently raised ~\$1000 to help them and other children go to Camp Hope. Kim presents PHACS CAB updates during site CAB meetings. During CAB meetings, staff members put on raffles. CAB members can win movie tickets and gift cards. The CAB also celebrates holidays together. CAB members help recruit new CAB members. CAB members also help encourage each other to continue to come to CAB meetings.

- **PHACS CAB NEWSLETTER, JUNE 2013 EDITION**

Megan talked about the PHACS CAB Newsletter, June 2013 Edition. The theme is support systems. Megan thanked the CAB for submitting articles to the newsletter. The newsletter will be sent out on Friday, June 28, 2013.

- **HEALTH EDUCATION AND COMMUNICATION COMMITTEE (HECC) UPDATE**

Claire talked about the PHACS website redesign. The design team is in process of making the website. The team is also making a website for young adults who will be in the new AMP 18+ study. PHACS leadership suggested naming the new study, “AMP Up.” The CAB approved of the name.

Claire talked about the Disclosure Books. Kimona and Jie are interns who will be working on the Disclosure Books. The Disclosure Books will help mothers/caregivers disclose their HIV-status to their children. The books will feature anonymous personal testimonials about disclosure. It will also have prompts that will help mothers/caregivers talk about disclosure with their children. There may also be a companion booklet for children. Claire encouraged CAB members to volunteer to review materials for the Disclosure Books. CAB members may also share their disclosure stories for the Disclosure Books.

Megan talked about the CAB Handbook. The CAB Handbook will be a resource for CAB members and site staff. It will talk about how to create a CAB and recruit and retain CAB members. The HECC CAB Subcommittee sent a survey to the Study Coordinators and received feedback about their site CABs. The HECC CAB Subcommittee will send a survey to CAB members to get feedback about their site CABs. The CAB will review survey responses during the July CAB conference call.

NOTE: The next CAB call will be on Thursday, July 25, 2013 at 12:00 pm EST.